

# **MEDIA RELEASE**

**NEWS FROM THE UNIVERSITY OF TASMANIA**

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ATTENTION: Chiefs of Staff, News Directors

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## **New report explores lasting effects of childhood cancer**

A University of Tasmania PhD sociology and social work student has completed a landmark, three-year study into the effects of childhood cancer on families.

As part of his research project, Terry Cox interviewed 38 Australian parents whose children had survived cancer.

Participants were interviewed at stages from five to 20 years after their child was first diagnosed.

With childhood cancer survival rates reaching nearly 80 per cent, Mr Cox said surprisingly little research had been undertaken into the long-term effects of childhood cancer on primary carers and family relationships.

He said there was a “cultural expectation” that families should “go back to normal” once their child had gone into remission.

“My key focus was on the period of time after a child was declared cancer free,” Mr Cox said.

“The primary carers, who are usually the parents, want to get back to some sort of normality, and are expected to get back to normal.

“Their doctors, social workers, nurses, family members and friends all tell them they should get back to normal because their child doesn’t have cancer anymore, but few people have examined what that normal might entail.

“What my research shows is that what these families reach is a ‘new normal’.

“It’s a life that is radically different from what they had envisioned.

“Their assumptions about life have changed dramatically, because you can’t ignore the precariousness of life and death, especially when it comes to your child.

“Speaking about these issues is part of the healing process for carers, but because there is so much emphasis on getting back to normal from friends and health professionals, they often simply put on a mask and act like everything is alright.

Mr Cox said his research had also shown the extent of many families’ ongoing battle with cancer treatment’s ‘late effects’ – the long term damage some treatments, such as chemotherapy, can wreak on the body.

“After cancer, many carers become late effects managers,” Mr Cox said.

“Chemotherapy can impact on a child’s normal brain development rate, so things like short term memory and concentration can be affected.

“That in turn affects a child’s education and career prospects later on.

“The parents are of course relieved and grateful towards medicine. But even with today’s advances in medicine, saving a child’s life from cancer can cause lasting damage.

“What needs to happen is medicine needs to legitimise late effects as a medical outcome of childhood cancer treatment.”

Mr Cox said children who had survived cancer needed better access to remedial services such as tutoring, physiotherapy and cosmetic surgery, along with specific care for vision, hearing, kidney, mobility and infertility problems.

Mr Cox said there should be a dedicated ‘post-cancer path’ for families to help them navigate their way through the services and support available.

Simon Rountree, chief executive of Camp Quality, the children’s family cancer charity, said:

“Camp Quality works closely with thousands of children who have been affected by cancer and their families and we are well aware of the challenges families face coping with the aftermath of cancer,” Mr Rountree said.

“This is why our education, recreational and family support programs continue to help families beyond remission.

“This report raises some interesting points and highlights the need for further support in this important area.”

Mr Cox said he planned to write a book based on his research.

“I think it would be very useful to families,” Mr Cox said.

“It would give them a better idea of what to expect, and to see how other survivors get on with life can be a powerful narrative for people in that raw situation of finding out their child has cancer.”

**For more information, to arrange interviews, or to obtain copies of the report, please call Luke Scott at the UTAS media office on (03) 6324 5019 or 0488 021 960.**

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